

# **Describing Target Audiences for Facility-Specific Quality Information Provided by Medicare**

## **Final Report**

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DESCRIBING TARGET AUDIENCES



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PUBLIC SERVICES

## EXECUTIVE SUMMARY

**Purpose:** To describe primary and secondary target audiences for the public release of facility-specific quality information provided by the Centers for Medicare & Medicaid Services (CMS), focusing on audiences for data relating to *nursing homes* and *home health care agencies* (priority areas for CMS) and on those target audiences who might have an incentive to use quality information for advance planning.

**Methodology:** The project team conducted a selective review of research as well as focus group research with representatives from the following groups of consumers and intermediaries involved with Medicare beneficiaries and their caregivers “upstream” in the planning and decision process:

- ◆ Caregivers<sup>1</sup> and/or Medicare beneficiaries who have sought information or support regarding their own or their loved ones’ future health care needs;
- ◆ General consumers who have demonstrated advanced planning for future needs; and
- ◆ Formal information intermediaries in the care and decision-making process who assist beneficiaries and caregivers in placement decisions.

A two-person study team conducted a total of 12 focus groups between July 10 and July 19, 2002, at three research sites: Camarillo, CA; Providence, RI; and Boston, MA.

**Selective Research Review:** Key findings from a review of 26 research reports and studies salient to this Subtask are summarized below.

### The challenge of older consumers

- ◆ The present cohort of older Americans has limited awareness of variations in health care quality.
- ◆ Most people judge quality based on the individual characteristics of their caregivers, rather than objective measures of clinical quality.
- ◆ Most older consumers and their caregivers respond to crises, instead of planning ahead for dependent care.
- ◆ Most older Americans tend to defer to the judgment of clinicians, rather than seek out information to make their own independent health care decisions.

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<sup>1</sup> For the purposes of this research, the term “caregiver” is defined as any friend or family member who has responsibility for the care and well-being of a person on Medicare, or who actively helps them make decisions about their health care, whether or not they provide direct physical care. In this instance, the term does not include persons who provide care as part of their professional responsibilities.

- ◆ Older Americans depend on family and friends as guardians, caregivers, sources of information, and surrogate decision makers.

#### Family and other caregivers

- ◆ The most common informal caregiving relationship is that of the adult child of elderly parents, followed by spouses and other relatives.
- ◆ Demographic characteristics of caregivers generally mirror those of the general population.
- ◆ Caregiving covers a spectrum of activities, but consumers often equate the term with personal hands-on care.
- ◆ Most caregivers balance work and family life, in addition to caring for elders.
- ◆ Many caregivers find it difficult to obtain needed services, both for financial reasons and because of the “hassle factor” associated with finding out what they need to know.
- ◆ Most caregivers know how to arrange for nursing home care, but few understand about the scope of services that encompass home health care.

#### Barriers to change

- ◆ Most elders and their caregivers are reluctant to anticipate, much less plan for, future dependency or long-term care needs, even in the face of apparent disability or functional decline.
- ◆ Many individuals feel ill prepared for the placement decision, even though they have long known that the need for such a placement is looming on the immediate horizon.
- ◆ Older people and their family caregivers are generally unfamiliar with the range of available services for dependent elders, except for nursing home care.

#### Trajectories of decline and triggers to action

- ◆ Family caregivers may fail to plan ahead because they become accustomed to intermittent crises and assume that their loved one will continue to bounce back.
- ◆ Hospitalization following acute episodes of illness may provide opportunities for health care providers to intervene in the lives of elderly patients at earlier stages to maintain as much independence as possible and slow the process of decline.

### Characteristics of advance planners

- ◆ Research on behaviors around facility placement provides little insight into the behaviors and motivations of those potential “early adopters” of quality information who *do* plan ahead.

### Understanding and using quality measures

- ◆ Consumers find it difficult to relate to quality measures as indicators of how well a facility performs in providing care.
- ◆ Most people have little or no experience with nursing homes, home health care agencies and other health care providers and have trouble understanding what it means to make choices among these health care providers.
- ◆ Health care professionals express concern about the potentially deleterious effects of public reporting of quality information.

## **Qualitative Research Findings**

### Characteristics and behaviors of advance planners and likely early adopters of quality information

- ◆ **Those most actively engaged in advance planning for needs relating to aging are men and women upon whom the responsibility for caregiving has fallen in the past.** Beneficiaries and caregivers who were most clear-sighted in their approach to future care needs were those who had shouldered the burden of caregiving for elders in the past. Many had taken care of a parent or a parent-in-law and knew from experience what to expect. This experience went a long way towards overcoming the denial and resistance common among family caregivers. Although women had more often assumed a caregiving role in the past, men also fell into this category. Many experienced caregivers were also only or eldest children. Experience caring for others also made these individuals more likely to plan for their own future.
- ◆ **Advance planners in this category have first-hand experience trying to gather information on long-term care alternatives and understand the value of good information.** Participants who had taken care of aging relatives told of how time-consuming it had been to track down information about available resources and care alternatives and described it as a “full-time job.” These individuals were far more knowledgeable than other consumers about available resources and sources of information, including information about quality.
- ◆ **Advance planning for needs related to long-term care and/or aging does not reflect a consumerist orientation, in general.** Advance planners were motivated by *experience*, not by consumerism, and few reported consumerist behavior in other aspects of their lives. Respondents also emphasized the difference between planning for long-term care and other major purchasing decisions: “Choosing a nursing home is not like choosing to buy a car.”

- ◆ **Male heads-of-household accustomed to assuming the fiduciary responsibilities of the family may represent a distinct category of individuals motivated to plan ahead for needs relating to aging, regardless of prior caregiving experience.** Although prior experience was the most striking characteristic shared by the advance planners interviewed for this project, a small number of male heads-of-household from relatively affluent backgrounds who lacked such experience appeared to be motivated to plan ahead by a more traditional paternalistic sense of responsibility for the family's welfare. They were also more likely to be active consumers of comparative information, generally. In contrast to advance planners with prior caregiving experience, however, these individuals also appeared to keep their emotional distance from the planning process, even when they had aging relatives for whom they were responsible. Notwithstanding their emotional distance and even denial, these individuals appeared to be receptive to factual information and to offers of help that allow them to engage in information gathering in a detached and systematic way.<sup>2</sup>
- ◆ **Men may assume the role of planners and information gatherers in the family, while women may assume the role of caregivers.** Several respondents suggested that there is often a sort of division of labor in families, such that women deal with the physical care and emotional issues and men gather information (which allows them to maintain their emotional distance). However, the limitations of this research study did not permit exploring this issue in depth.
- ◆ **Advance planning for funerals is common, but it is not associated with advance planning for health care or other needs related to aging.** Planning for funerals did not necessarily indicate a realistic approach to dependency needs related to aging or a willingness to plan ahead for such contingencies. Death is recognized as inevitable, but the declining health and dependency that precede death are not topics most people care to think about.
- ◆ **Only children, especially those who are single, may also recognize the need to plan ahead, but they often do not know what to expect or where to turn for help.** Only children recognized that they were the ones who would have to take care of their parents if something were to happen, but they still found it difficult to think about what might happen and seemed reluctant to take action until serious problems arose. Most nevertheless thought that having information available early on would be useful.

#### Triggers to action

- ◆ **Witnessing problems relating to aging and functional decline in other persons' relatives can prompt concern about one's own aging relative or loved one.** Although all respondents commented on the difficulty of coming to terms with their parent's or spouse's functional decline and dependency, many exhibited *no* difficulty recognizing this trajectory

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<sup>2</sup> Because only a small number of respondents displayed these characteristics, the observations offered here are merely suggestive. Further research would be needed to probe whether such individuals may be true early adopters of quality information.

and its implications when it occurred in in-laws or other people's relatives. Hospital discharge planners also reported that adult children sometimes approached them for information about long-term care alternatives after visiting the ailing relatives of long-time friends. This suggests an inverse relationship between the level of intimacy between the caregiver and the aging relative and the ability to acknowledge functional decline and dependency.

- ◆ **Experienced caregivers and information intermediaries recognize triggers of concern further “upstream” in the trajectory of functional decline.** Respondents who were experienced caregivers as well as hospital discharge planners were more likely than others to recognize relatively subtle signs and signals that occurred long before there were serious signs of decline. These triggers of concern included moving to be close to adult children, loss of a car and/or driver's license, or an unwillingness to drive.
- ◆ **Most caregivers who lack prior experience delay taking action until there are more obvious signs of decline, further “downstream” in the process.** Most identified triggers of concern were associated with serious states of decline that virtually demanded intervention, including hospitalization, falls or serious mobility problems, leaving things burning on the stove, not eating, wandering, or not answering the telephone. When pressed, however, respondents reported noticing earlier signs of decline, such as deteriorating personal hygiene or housekeeping, to which they had failed to respond.

#### Perceived informational needs and concerns about quality

- ◆ **Most caregivers express the need, first, for information about available services and covered benefits. Concerns about quality arise once they have a clearer understanding of available alternatives.** Unless they have prior experience, most caregivers know very little about the kinds of services that are available, how much they cost, what is covered, and how they can be paid for. However, all caregivers agreed that quality was a major concern, once they understood their alternatives.
- ◆ **Most caregivers are interested in information relating to quality of care in nursing homes.** Concerns about the quality of care in nursing homes, fueled more often by media images of sensational cases rather than personal experience, often reinforce caregivers' natural resistance to considering nursing home placement for their parents or spouses. Yet these concerns have the effect of raising caregivers' awareness and may be a motivating factor about the importance of quality measures, creating an opportunity for communicating about variations in quality. Several respondents commented that they would be receptive to information about *good* nursing homes and acknowledged that inherent feelings of guilt about placing their parents would be minimized if they knew that such alternatives existed.
- ◆ **Caregivers' concerns about home health care services relate more to discomfort with “strangers in the house” than to concerns about quality.** In contrast to the concerns they expressed about nursing home care, caregivers raised few questions about the quality of home care services. Instead, what they mentioned most often was their discomfort with having strangers come into their parents' house, even when their parents seemed to enjoy the

company. Surprisingly, this aversion to care in the home was sometimes stronger than the caregivers' aversion to assisted living or institutional long-term care.

- ◆ **Caregivers and intermediaries express interest in comparative facility-specific information about quality, but they are most likely to use it in conjunction with other, more subjective, sources of information.** Most respondents stressed that they made judgments about quality (and would continue to do so) based on other information – including cost, the recommendations of family, friends, and health professionals, and their own personal observations. Hospital social workers and discharge planners urged family members to visit nursing homes and make their own judgments, based on their personal observations.
- ◆ **Although hospital social workers and discharge planners are important sources of information to family caregivers, caregivers who are most actively engaged in advanced planning activities for their family members seek information from many, varied, and disparate sources.** Hospital-based intermediaries usually become involved after a family member has experienced a sentinel event in the trajectory of decline. Experienced caregivers therefore stressed the importance of gathering information in many different ways and from many different sources. No single source of information emerged from these experiences as most important or primary.

#### Implications for Communication Strategies: Messages and Channels

- ◆ **Target “early adopters” and advance planners as the primary caregiver audience.** This research suggests that *experienced caregivers* are a primary target audience for facility-specific quality information from Medicare who can be described as “advance planners.” *Male heads-of-household* may also represent a distinct group of potential early-adopters of quality information, regardless of prior experience, although additional research would be needed to support this observation.
- ◆ **Frame messages to tap into the personal characteristics and motivations of target audiences.** *Experienced caregivers* appear to understand, from past experience, how difficult it is emotionally to deal with a loved one's functional decline and loss of independence. They may therefore be responsive to messages that acknowledge and tap into this emotional realism. *Male heads-of-household*, who lack past experience with caregiving, however, may *not* be emotionally prepared to deal with a loved one's functional decline. They may consequently *resist* messages based on an emotional appeal, but respond to those that appeal to their rational side and their sense of paternalism, allowing them to retain their emotional distance.
- ◆ **Target “contemplators”<sup>3</sup>, such as only children or sole caregivers, as a secondary caregiver audience.** Only children or others who are the sole caregivers of elderly relatives may recognize that they will be responsible for taking care of aging relatives and making

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<sup>3</sup> The term “contemplator” refers to the stage model of behavior change discussed in greater detail in the Introduction to the full report.

decisions about home care or nursing home placement, but they may lack the emotional readiness or the motivation to take action until they are forced to do so. These individuals fall into the categories of *contemplators*, and, because they are more difficult to reach, may be regarded a secondary target audience among caregivers.

- ◆ **Frame messages to move “contemplators” to action by honing in on triggers, while acknowledging their emotional resistance.** The challenge in motivating *contemplators* to take action lies in getting them to recognize potential needs before they reach the crisis stage, and to recognize that planning ahead for such needs does not constitute a betrayal of their loved ones. They may be responsive to messages that acknowledge their emotional resistance but focus on “upstream” signs or triggers that advance planners have identified, stressing the advantages of planning ahead.
- ◆ **Target hospital social workers, physicians and discharge planners as a primary intermediary audience.** Hospital social workers and discharge planners are consistently identified by caregivers as playing an important role in the decision-making process and should therefore be considered the primary target audience among information intermediaries.
- ◆ **Frame messages to encourage intermediaries to engage in anticipatory guidance with family caregivers, focusing on “upstream” issues.** Experienced hospital social workers and discharge planners are in an excellent position to provide anticipatory guidance to family members. However, the demands of their jobs may be such that they focus more often on the immediate need to arrange post-hospital care rather than on longer-term care considerations. The challenges, then, are to build on their sense of professionalism to define their roles in larger terms and to provide them with easy-to-use tools, so as to minimize the additional burden that this new role would entail.
- ◆ **Disseminate information through a variety of channels in the local community, to reach family caregivers and raise their awareness before they are in crisis.** Caregivers reported spending a great deal of time sitting and waiting while they accompanied their family members to various appointments and suggested that they would be likely to notice information relating to caring for aging relatives at those times. Doctors’ offices, emergency room waiting rooms, and pharmacies were mentioned most often, along with libraries, post offices and other community locations.
- ◆ **Acknowledge and build on concerns about the care provided in nursing homes to promote interest in quality.** Concerns about quality of care in nursing homes may provide a “hook” for prompting discussion and raising awareness about variations in quality performance and about measures of quality. Messages might acknowledge concerns, but offer positive solutions. Respondents commented that most of what they hear about nursing home quality is through the media and is usually “bad.” However, they were open to hearing about “good” quality nursing home facilities from other reliable sources.
- ◆ **Frame messages around quality information within the context of larger issues related to planning.** Facility-specific quality information provided by Medicare cannot help

consumers make meaningful decisions by itself. It should be promoted as *part of* a larger set of information about costs, benefits, and quality of services for the elderly, including those that are not covered by Medicare.